



Cleft Lip and Cleft Palate

What are cleft lip and cleft palate?

- Cleft lip/palate occurs when a baby's lip or mouth do not form properly during pregnancy. It is the fourth most common birth defect and occurs in 1 in every 1,600 babies in the United States.
- A cleft lip is a separation of the upper lip. The cleft can occur on one or both sides of the lip. A cleft palate is a separation of the top of the mouth. Like cleft lip, the cleft palate also can occur on one or both sides of the top of the mouth
 - Many times, someone who has a cleft lip also will have a cleft palate.

What causes cleft lip and cleft palate?

- The causes of clefts among most infants are unknown, but some are believed to be due to changes in their genes, or a combination of other factors, like things the mother comes in contact within her environment or what the mother eats or drinks. Recent research studies have also found some factors increase the chance of having a baby with a cleft, such as:
 - ✓ smoking
 - ✓ diabetes
 - ✓ use of medications during pregnancy
- Regular prenatal care can help reduce the risks of birth defects.
- Parents often want to learn more about the chance of having another child with a cleft. Specialized medical providers, called genetic counselors, can help give you this information.

How are cleft lip and cleft palate treated?

- Those with cleft lip and cleft palate are usually treated with surgery when they are a baby.
- Parents should consult a cleft lip/palate specialist team. This team of professionals will work with you, your baby, and your family doctor to make sure your baby gets the best care possible.
 - ✓ Teams can be located by calling the Cleft Palate Foundation at (800) 242-5338.

Are there special feeding issues for babies born with cleft lip or cleft palate?

- A baby with only cleft lip usually does not experience feeding problems other than learning to latch to the nipple at the start of the feeding. Special nipples are available to assist with feeding.
- A baby with both a cleft lip and cleft palate may need to be fed differently due to the open area between the nose and mouth.
- It is best to hold the baby in an upright position while feeding to decrease the chance of milk

leaking into the nose.

- Cleft palate babies also may swallow more air, needing to burp more.

The important point to remember is that the baby needs to receive proper nutrition through feeding. The baby's weight should be checked on a regular basis by a doctor to know the baby is gaining adequate weight.

Will a child with cleft lip or cleft palate have special dental needs?

- Children with cleft lip or cleft palate require early evaluation by a dentist familiar with their special needs. These children may have problems with poorly positioned, malformed, or missing teeth. With early detection and intervention, children with cleft lips or cleft palates can lead normal, healthy lives.

Where can a person learn more about cleft lip/cleft palate?

- The Cleft Palate Foundation is a public service and education organization that provides services to patients and families. It also distributes informational brochures and fact sheets on clefts.
 - ✓ The foundation's 24-hour toll-free hotline is (800) 242-5338.
- The University of Illinois' Division of Specialized Care for Children (DSCC) provides information and can refer patients and families to its nearest office for help. Call (800) 322-3722
- The Illinois Early Childhood Intervention Clearinghouse provides library and information services about early childhood and disability issues. They can be reached at (800) 852-4302.

Resources

NOTE: This fact sheet was derived from one previously published by the Arizona Department of Health Services.

American Cleft Palate-Craniofacial Association
<https://acpa-cpf.org/>

Centers for Disease Control and Infection
<https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html>

Illinois Cleft and Craniofacial Teams

Cleft and Craniofacial Team – [CPT, CFT](#)
Shriners Hospital for Children
2211 N Oak Park Ave
Chicago, IL 60707-3351
Team Phone: 773.385.5405
Team Fax: 773.385.5830

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Team Email: mogara@shrinenet.org

Team Website: <http://www.shrinershospitalsforchildren.org/Hospitals/Locations/Chicago/CleftLip.aspx>

Patient Age Range: 0-21

Team Leader(s): Pravin K. Patel, MD (Plastic Surgery)

Team Coordinator(s): Mary M. O’Gara, MA, CCC-SLP (Speech-Language Pathology)

Cleft Lip and Palate/Craniofacial Team – [CPT, CFT](#)

Lurie Children’s Hospital of Chicago

225 E Chicago Ave

Box 93

Chicago, IL 60611-2991

Team Phone: 312.227.6250

Team Fax: 312.227.9408

Team Email: lduffy@luriechildrens.org

Team Website: <https://www.luriechildrens.org/en-us/care-services/conditions-treatments/fetal-cleft-lip-palate/Pages/index.aspx>

Patient Age Range: 0-21

Team Leader(s): Arun K. Gosain, MD (Plastic Surgery)

Team Coordinator(s): Linda L. Duffy, RN, CPN, CPSN (Nursing)

Craniofacial Center – [CPT, CFT](#)

University of Illinois Hospital and Health Sciences System

811 S Paulina St

MC 588 / Suite 161

Chicago, IL 60612-4353

Team Phone: 312.996.7546

Team Fax: 312.413.1157

Team Email: tkaislin@uic.edu

Team Website: http://hospital.uillinois.edu/Patient_Care_Services/Craniofacial_Center.html

Patient Age Range: 0-99

Team Leader(s): Mimis Cohen, MD (Plastic Surgery)

Team Coordinator(s): Terri G. Kaisling, RN, MBA (Nursing); Alma A. Moya, RN (Nursing)

Rush Craniofacial Center – [CPT, CFT](#)

1725 W Harrison St Ste 425

Chicago, IL 60612-3893

Team Phone: 312.563.3000

Team Fax: 312.563.2514

Team Email: nicole_b_heller@rush.edu

Team Website: <http://www.rush.edu/patients/plasticsurgery/craniofacial>

Patient Age Range: 0-99

Team Leader(s): Alvaro A. Figueroa, DDS, MS (Orthodontics); Christina Tragos, MD (Plastic Surgery)

Team Coordinator(s): Nicole Heller, (Plastic Surgery)

University of Chicago Cleft Lip and Palate Clinic and Craniofacial Anomalies Multidisciplinary Program (CAMP) – [CPT, CFT](#)

5841 S Maryland Ave

Mc 6035.

Chicago, IL 60637-1447
Team Phone: 773.795.4525
Team Fax: 773.702.1634
Team Email: jcao1@surgery.bsd.uchicago.edu
Team Website: <http://www.uchicagokidshospital.org/specialties/craniofacial>
Patient Age Range: 0-21
Team Leader(s): Russell R. Reid, MD, PhD (Plastic Surgery)
Team Coordinator(s): James Cao, (Coordinator/Administrator); Kelly Postmas, RN, BSN (Nursing);
Lisa Skiba, RN, BSN (Nursing)

Advocate Children's Hospital Cleft and Craniofacial Team – [CPT](#)

1675 Dempster St
3rd Floor
Park Ridge, IL 60068-1110
Team Phone: 847.723.7308
Team Fax: 847.723.9457
Team Email: christine.provenzano@advocatehealth.com
Team Website: <http://www.advocatehealth.com/>
Patient Age Range: 0-21
Team Leader(s): Frank A. Vicari, MS, MD, FACS, FAAP (Plastic Surgery); James W. Weedon, MD
(Pediatrics)
Team Coordinator(s): Ady DeLaGarza, CMA (Coordinator/Administrator); Christine Provenzano, RN
(Nursing)

Central Illinois Orofacial Anomalies Team – [CPT](#)

507 E Armstrong Ave
Peoria, IL 61603-3201
Team Phone: 309.686.1177
Team Fax: 309.686.7722
Team Email: tarahood@ci.easterseals.com
Team Website: <http://www.ci.easterseals.com>
Patient Age Range: 0-21
Team Leader(s): Eric T. Elwood, MD (Plastic Surgery)
Team Coordinator(s): Tracey Arahood, (Coordinator/Administrator)

SIU Congenital Head & Neck Anomalies Clinic – [CPT](#)

747 N Rutledge St
PO Box 19653
Springfield, IL 62702-6700
Team Phone: 217.545.7031
Team Fax: 217.545.2588
Team Email: ppraia@siumed.edu
Team Website: <http://www.siumed.edu/surgery/plastics>
Patient Age Range: 0-21
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Team Leader(s): Kevin A. Calder, MD, FRCSC (Plastic Surgery)
Team Coordinator(s): Penny Praia (Coordinator/Administrator)

Carle Cleft Lip and Palate Team – [CPT](#)

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602 W University Ave
Urbana, IL 61801-2530
Team Phone: 217.383.4383
Team Fax: 217.383.4468
Team Email: jayne.wachtel@carle.com
Team Website: <http://www.carle.org/services/cleft-lip-palate.aspx>
Patient Age Range: 0-18
Team Leader(s): Jonathan S. Bailey, MD, DMD, FACS (Oral/Maxillofacial Surgery)
Team Coordinator(s): Jayne Miller Wachtel, MA (Speech-Language Pathology)

Missouri Cleft and Craniofacial Team serving Southern Illinois Residents

Cleft Lip/Palate and Craniofacial Deformities Center – [CPT, CFT](#)
Mercy Children’s Hospital
621 S New Ballas Rd Ste 281A
Saint Louis, MO 63141-8256
Team Phone: 314.251.6581
Team Fax: 314.251.5772
Team Email: dana.kiley@mercy.net
Team Website: <http://www.mercy.net/practice/mercy-clinic-kids-plastic-surgery>
Patient Age Range: 0-99
Team Leader(s): Earl A. Gage, MD (Plastic Surgery)
Team Coordinator(s): Dana M. Kiley, BS (Coordinator/Administrator)

Cleft Palate and Craniofacial Institute – [CPT, CFT](#)
St Louis Children’s Hospital
1 Childrens Pl
Nwt Ste 1150
Saint Louis, MO 63110-1002
Team Phone: 314.454.6063
Team Fax: 314.361.4571
Team Email: scheves@wudosis.wustl.edu
Team Website: <http://www.stlouischildrens.org/our-services/cleft-palate-and-craniofacial-institute>
Patient Age Range: 0-99
Team Coordinator(s): Sibyl V. Scheve, RN, BSN (Nursing)

St. Louis Cleft-Craniofacial Center – [CPT, CFT](#)
Cardinal Glennon Children’s Medical Center at Saint Louis University
1465 S Grand Blvd
Glennon Hall 3707
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Saint Louis, MO 63104-1095
Team Phone: 314.577.5368
Team Fax: 314.268.2714
Team Email: Joy.Baltz@ssmhealth.com

Team Website: <http://www.cardinalglennon.com/medicalspecialties/cleftlip/pages/default.aspx>
Patient Age Range: 0-99

Team Leader(s): Alexander Y. Lin, MD (Plastic Surgery)

Team Coordinator(s): Joy Baltz, RN, BSN (Nursing)

The Cleft Palate Internet Sources.

American Cleft Palate-Craniofacial Association (ACPA)

For professional information on cleft lip/palate, including an explanation of the importance of team treatment of these birth anomalies.

www.cleftpalate-craniofacial.org

Cleft Palate Foundation:

Operates a 24-hour hotline assisting parents and adult patients with questions about cleft lip and palate and other craniofacial anomalies. CPF also provides referrals to cleft palate/craniofacial teams, distributes free educational publications, and awards annual scientific research grants.

www.cleftline.org, info@cleftline.org

Cleft Advocate:

A resource providing general information and networking, as well as advice for people who are fighting insurance denials for their medical care. Has the Pathfinders program, an outreach network that helps families find answers based on local services and experiences, and a state resource guide. www.cleftadvocate.org Debbie@cleftadvocate.org

FACES – The National Craniofacial Association:

Provides support to people with craniofacial differences through newsletters, information packets, and financial assistance for non-medical costs.

www.faces-cranio.org, faces@faces-cranio.org

Foundation of Facial Reconstruction:

Provides comprehensive medical treatment, psychological counseling, research and education through the Institute of Reconstructive Plastic Surgery at NYTU www.nffr.org

Fresh Start Caring for Kids Foundation:

Medical care, healthcare services and procedures are provided through Surgery Weekends. Medical services will vary by location and will change over time. If you have a question about a specific medical procedure, please contact us.

<http://www.freshstartkids.org/medical-services/>

Web Ring by and for Families experiencing Facial Clefts “The AmeriFace Circle of Smiles”

A welcome on-line resource for parents and families dealing with cleft lip and palate. Founded by a parent who addresses health care and health insurance issues, family to family networking and articles. A family-to-family chat group is also sponsored by this website.

www.hub.webring.org/hub/wide_smiles

Specialized Training of Military Parents (STOMP):

Provides international medical information and training to military families who have children with special needs.

www.stompproject.org

Children's Craniofacial Association:

CCA addresses the medical, financial, psychosocial, emotional, and educational concerns relating to craniofacial conditions.

www.ccakids.org

Cleft Meetup:

An online message board helping to facilitate monthly face-to-face meetings among people in their own local areas.

www.cleft.meetup.com